It Takes a Village: Caring for Veterans with Advanced Dementia

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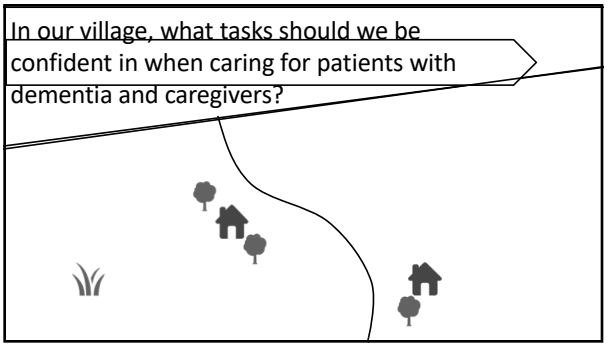
In our village, what tasks should we be confident in when caring for patients with dementia and caregivers?



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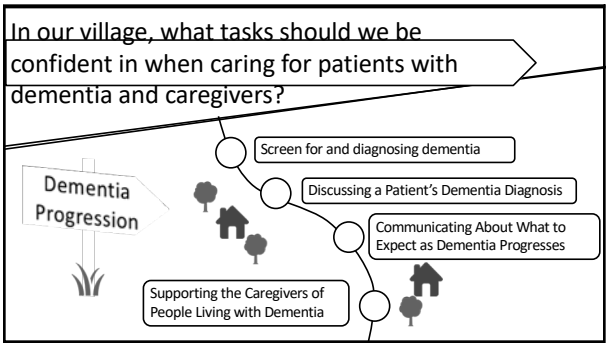

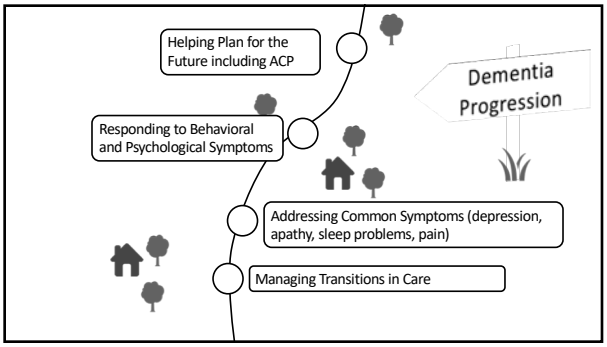

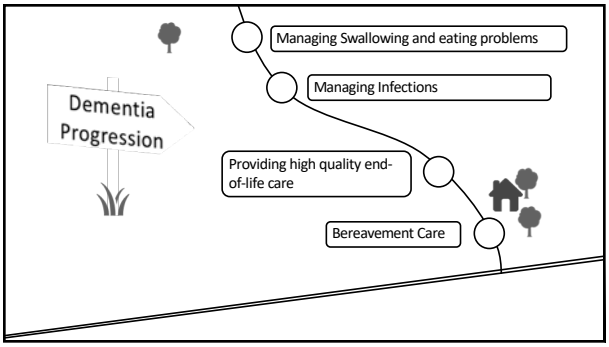

Center to Advance Palliative Care™
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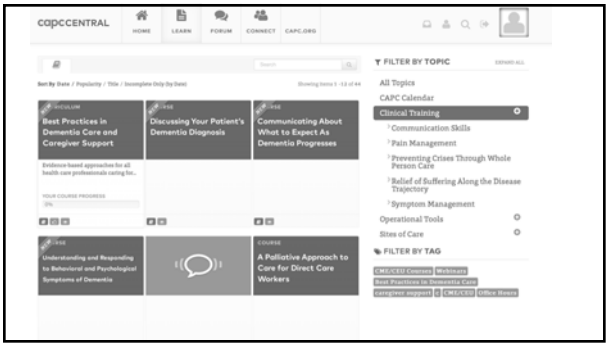

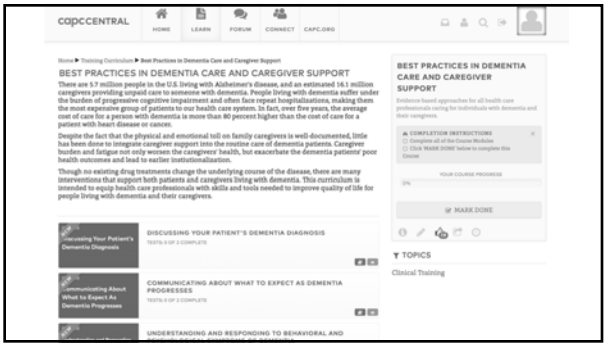

Interprofessional Dementia Curriculum

- Discussing Your Patient's Dementia Diagnosis
- Communicating About What to Expect as Dementia Progresses
- Understanding and Responding to Behavioral and Psychological Symptoms of Dementia
- Supporting the Caregivers of People Living with Dementia
- Planning for the Future with People Living with Dementia and their Caregivers
- Addressing Mood and Sleep Disturbances for People Living with Dementia
- Addressing Swallowing Disorders, Pain, and Medical Decision-Making for People Living with Dementia

Henry

Henry is a 88 year old Veteran diagnosed with Alzheimer's disease 7 years ago. He was admitted to a nursing home for long term care 6 months ago.

He enjoys listening to music and occasionally sings along, but otherwise can only speak a few words.

He no longer recognizes his daughter, and is unable to independently perform any activities of daily living.

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He has been having increasing weight loss over the last 3 months. He shows little interest in food and is having increasing difficulty with eating. He pockets food and occasionally coughs while eating meals.

He is now admitted to the hospital with fever and diagnosed with suspected pneumonia.

Henry

On admission placed on honey-consistency liquids for concern for aspiration (he was prescribed this at the nursing home)

During the first week of hospitalization, he has refused nearly all foods and liquids.

He is becoming more confused and agitated, and hit a nurse during meal time. He also has been noted to be sleeping during the day and awake at night

What is the best next step in Henry's care

1. Start olanzapine for agitation and sleep
2. Start hospice care
3. Speech consult for evaluation whether he can safely eat
4. Meet at a team to further describe behaviors
5. Place a PEG for weight loss
6. Start dextromethorphan quinidine (Nuedexta)

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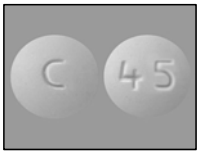


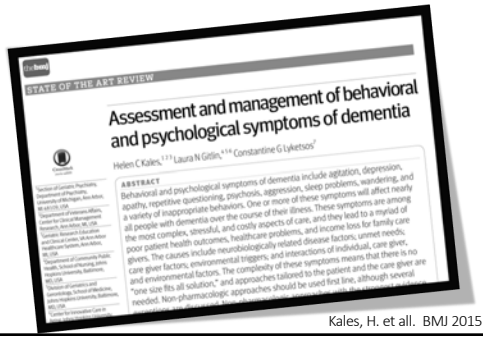
2

Don't use antipsychotics as the first choice to treat behavioral and psychological symptoms of dementia.

People with dementia often exhibit aggression, resistance to care and other challenging or disruptive behaviors. In such instances, antipsychotic medicines are often prescribed, but they provide limited and inconsistent benefits, while posing risks, including over sedation, cognitive worsening and increased likelihood of falls, strokes and mortality. Use of these drugs in patients with dementia should be limited to cases where non-pharmacologic measures have failed and patients pose an imminent threat to themselves or others. Identifying and addressing causes of behavior change can make drug treatment unnecessary.

DICE:

An Interprofessional 4-step approach to managing behavioral symptoms in patients with dementia



STATE OF THE ART REVIEW

Assessment and management of behavioral and psychological symptoms of dementia

Helen C Kales,[1 2 3] Laura N Gitlin,[4 5 6] Constantine G Lyketsos[7]

ABSTRACT

Behavioral and psychological symptoms of dementia include agitation, depression, apathy, repetitive questioning, psychosis, aggression, sleep problems, wandering, and a variety of inappropriate behaviors. One or more of these symptoms will affect nearly all people with dementia over the course of their illness. These symptoms are among the most complex, stressful, and costly aspects of care, and they lead to a myriad of poor patient health outcomes, healthcare problems, and income loss for family care givers. The causes include neurobiologically related disease factors, unmet needs, care giver factors, environmental triggers, and interactions of individual, care giver, and environmental factors. The complexity of these symptoms means that there is no "one size fits all solution," and approaches should be used first line, although several needed. Non-pharmacologic approaches tailored to the patient and the care giver are

Kales, H. et all. BMJ 2015

Step 1: Describe

Describe Investigate Create Evaluate

A

B C

Describe Investigate Create Evaluate

A

B C

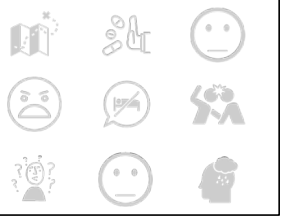
Antecedent:
What led up to the behavior or might have triggered it?

Describe Investigate Create Evaluate

A

B C

Behavior:



Describe Investigate Create Evaluate

A

B C

Behavior:
What was the behavior?
Where and when did it occur?
How often is it occurring?

Describe Investigate Create Evaluate

A

B **C**

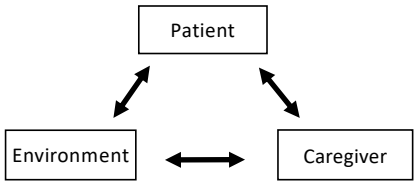
Consequences:
What happened after the behavior? What was problematic or distressing about it?

Describe Investigate Create Evaluate

Step 2: Investigate

Explore possible causes for the behavior.

Behavioral symptoms arise from a complex interaction between patient, caregiver, and the environment



Behavioral symptoms arise from a complex interaction between patient, caregiver, and the e

Common Patient Factors

- Undiagnosed medical illness
- Adverse medication effects
- Unmet needs (i.e. hunger, thirst)
- Untreated symptoms
- Depression, anxiety
- Feeling out of control
- Being overwhelmed or asked to do more than able
- Hearing or vision loss, or limitations in functional abilities
- Routines from the past

Behavioral symptoms arise from a complex interaction between patient, caregiver, and the environment

Common Environmental Factors

- Over- or under-stimulating environment
- Unsafe or challenging environment to navigate
- Daily routines that are not aligned with patient preferences
- Lack of pleasurable activities
- New or changing environment
- New or changing caregivers

giver

Behavioral symptoms arise from a complex interaction between patient, caregiver, and the environment

Common Caregiver Factors

- Poor understanding of the illness leading
- Over or underestimation of the patient's abilities
- Lack of education about how to respond to dementia-related behaviors
- Lack of education about effective communication strategies (i.e. avoiding arguing, complex instructions, or frequent corrections)
- Caregiver stress, burden, and emotional health
- Difficult prior relationship

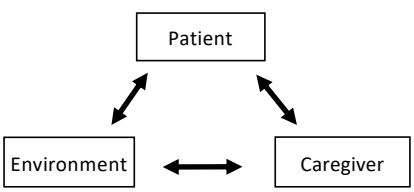
Er

Describe **Investigate** **Create** **Evaluate**

Step 3: Create

Create a care plan that matches the identified precipitants of the behaviors.

Describe **Investigate** **Create** **Evaluate**



Describe Investigate Create Evaluate

Common Patient-Focused Interventions

- Treat for pain or other symptoms (e.g. constipation)
- Manage underlying illness such as depression or infection
- Discontinue medications to limit side effects
- Address unmet needs (hunger, thirst, boredom, poor sleep)

Describe Investigate Create Evaluate

Common Caregiver Focused Interventions

- Teach caregivers that dementia behaviors are not intentional or in the patient's control
- Educate them about the common causes of dementia-related behaviors
- Remind caregivers that emotions are contagious – in both directions
- Address caregiver mental health (burden and depression)

Describe Investigate Create Evaluate

Common Environmental Interventions

- Maintain consistent, familiar environment and caregivers
- Reduce loud or unidentifiable noises
- Simplify tasks
- Remove clutter, avoid shiny door knobs, remove mirrors if upsetting
- Use simple visual reminders to facilitate common tasks
- Introduce activities that tap into preserved capabilities and previous interests

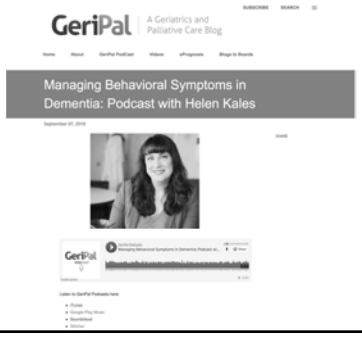
Describe Investigate Create Evaluate

Should Pharmacologic Therapy Be In the Plan?

Describe Investigate Create Evaluate

Step 4: Evaluate

Monitor whether the prescribed individualized therapies were implemented - and whether they were effective.



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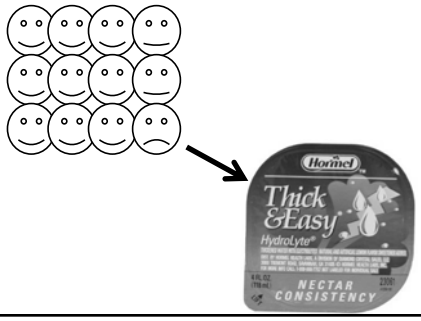
Why Is He Having Weight Loss?

M	Medications
E	Emotional issues (i.e. depression)
A	Anorexia
L	Late-life paranoia or alcoholism
S	Swallowing disorders
O	Oral factors
N	No money
W	Wandering (in patients with dementia)
H	Hyperthyroidism, hyperparathyroidism
E	Entry problems/malabsorption
E	Eating problems (severe tremor, stroke, weakness)
L	Low-salt or low-cholesterol diets
S	Shopping and food preparation problems

Medications and weight loss

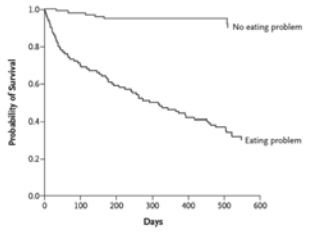
- Anorexia
  - Digoxin
  - SSRI
- Dysgeusia
  - Statins
  - Phenytoin
  - Anything that dry's the mouth
- Cholinesterase Inhibitors
- Dysphagia
  - Bisphosphonates
  - Anti-cholinergics
- Nausea
  - SSRIs
  - Digoxin
  - Opioids
  - Vitamins (ie Zinc, Iron)
- Just Plain Bad Taste



Other Reasons in Advanced Dementia

- 86% will develop eating Problems
  - Refusal to eat (disinterest, lack of hunger, depression)
  - Apraxia (difficulty with motor movement)
  - Oropharyngeal dysphagia

NH Residents with Advanced Dementia



N Engl J Med. Oct 15 2009

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So how should we manage swallowing problems?

Placement of a PEG

Keep NPO

Speech consult to evaluate if he can safely eat

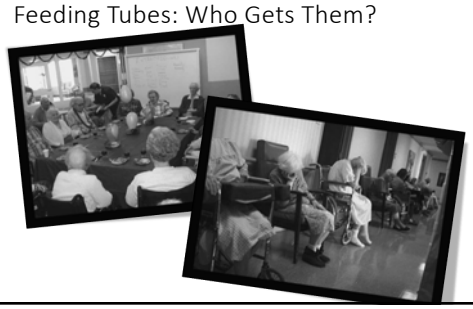
Careful Hand Feeding

Evidence Base for Feeding Tubes

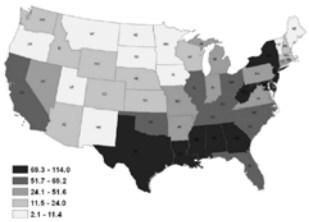
- No RCTs
- 7 observational controlled studies showed no evidence of:
  - Increased survival
  - Decreased mortality
  - Improved quality of life
  - Improved nutritional parameters (weight, albumen)
  - Physical functioning,
  - Improvement or reduced incidence of pressure ulcers

Sampson EL, Candy B, Jones L. Cochrane Database of Systematic Reviews 2009

Feeding Tubes: Who Gets Them?



One Year Incidence of Tube Insertion Per 1,000 NH Residents with Advanced Dementia



- J Am Med Dir Assoc. 2009 May ; 10(4): 264–270

Where do they get them?

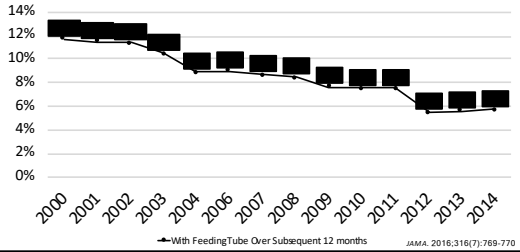
Characteristics of Hospitals.

- 2/3rd of patients with advanced dementia have their feeding tube inserted during an acute care hospitalization

  J Am Med Dir Assoc. 2009 May ; 10(4): 264–270
- In a study of NH residents admitted to the hospital:
  - Rate of feeding tube insertion varied 0 to 38.9 per 100 hospitalizations
  - Higher rates in for-profit hospitals that were large and had more ICU use in the last 6 months of life

  JAMA. 2010;303(6):544-550

Feeding Tube Insertion Rates Among US Nursing Home Residents with Advance Dementia



JAMA. 2016;316(7):769-770

Informed Consent for Feeding Tubes in Dementia

- 486 next-of-kin of decedents
- Of those who received a feeding tube:
  - 14% reported no discussion before feeding tube insertion
  - Discussion of the risks of feeding tube insertion occurred in only half of the cases.
  - In 1/3rd of cases, the possibility of hand-feeding was not discussed
  - 26% stated the feeding tube was inserted to make it easier for staff to feed the patient.

J Am Geriatr Soc. 2011 May;59(5):881-6

HARMS

- 26% were physically restrained after feeding tube placement.
- 29% needed sedating medications to prevent them from pulling out the feeding tube
- 40% of family members stated that the feeding tube seemed to bother the patient.
- Nearly a quarter (23%) of family members stated that they regretted the decision to insert the feeding tube.

J Am Geriatr Soc. 2011 May;59(5):881-6

Alternative: Not NPO - Careful Hand feeding

- Pros
  - Maintains pleasure of tasting food
  - Participation in meal times
  - Increases interactions with patients
- Cons
  - Labor Intensive

Choosing Wisely
An initiative of the ABIM Foundation

American Academy of Hospice and Palliative Medicine
AAHPM

Five Things Physicians and Patients Should Question

Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.

In advanced dementia, studies have found feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacological restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems; in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than nutritional goals.

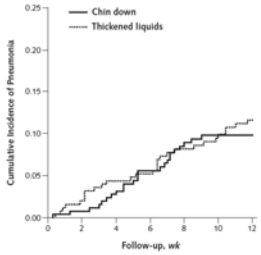
Wait, what again about Thickened Liquids?

Aspiration and Dysphagia

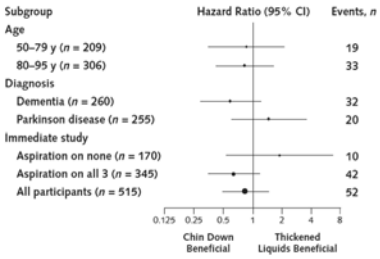
- 515 patients with dementia or Parkinson's disease with aspiration on VFSS
  - Randomized to chin-down position, nectar-thick liquids, or honey-thick liquids
  - Followed for 3 months

Robbins J et al. (2008). *Ann Intern Med , 148* (7), 509-518.

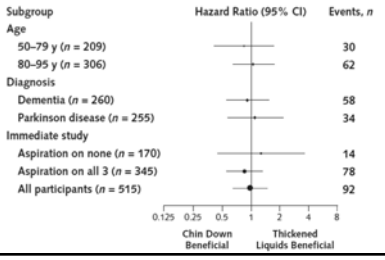
Results: no difference in pneumonia



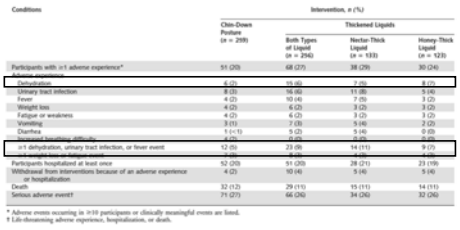
Results: effect on pneumonia



Results: effect on pneumonia or death



Harms of Thickened Liquids



Conditions	Intervention, n (%)			
	Chin-Down Posture (n = 259)	Thickened Liquids		
		Both Types of Liquid (n = 256)	Nectar-Thick Liquid (n = 193)	Honey-Thick Liquid (n = 123)
Participants with ≥1 adverse experience*	51 (20)	68 (27)	38 (29)	30 (24)
Adverse experience				
Dehydration	6 (2)	16 (6)	7 (4)	8 (7)
Urinary tract infection	8 (3)	16 (6)	11 (8)	5 (4)
Fever	4 (2)	10 (4)	7 (5)	3 (2)
Weight loss	4 (2)	6 (2)	3 (2)	3 (2)
Fatigue or weakness	4 (2)	6 (2)	3 (2)	3 (2)
Vomiting	3 (1)	7 (3)	5 (4)	2 (2)
Diarrhea	1 (<1)	5 (2)	5 (4)	0 (0)
Increased breathing difficulty	4 (2)	5 (2)	5 (4)	0 (0)
≥1 dehydration, urinary tract infection, or fever event	12 (5)	23 (9)	14 (11)	9 (7)
≥1 weight loss or fatigue event	4 (2)	8 (3)	4 (3)	4 (3)
Participants hospitalized at least once	52 (20)	51 (20)	28 (21)	23 (19)
Withdrawal from interventions because of an adverse experience or hospitalization	4 (2)	10 (4)	5 (4)	5 (4)
Death	32 (12)	29 (11)	15 (11)	14 (11)
Serious adverse event†	71 (27)	66 (26)	34 (26)	32 (26)

* Adverse events occurring in ≥10 participants or clinically meaningful events are listed.
† Life-threatening adverse experience, hospitalization, or death.

Robbins J et al. (2008). *Ann Intern Med , 148* (7), 509-518.

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Return to the case

Henry's daughter, who is the appropriate surrogate, agrees that Henry would not have wanted a feeding tube and what is most important right now is his comfort. She though is worried about what would happen if he continues to have problems swallowing and develops and infection.

She asks: Would we still send him to the hospital and treat him with antibiotics if she develops a pneumonia?

Which of the following are statements is best supported by the literature regarding the use of antibiotics for pneumonia in individuals like Henry with advanced dementia?

a) They prolong life
b) They improve comfort
c) They are most effective given intravenously

Evidence from observational studies looking at antibiotics for pneumonia

Evidence from observational studies looking at antibiotics for pneumonia

Patients with advanced dementia who are treated with antibiotics may live several months longer than those who are untreated

Evidence from observational studies looking at antibiotics for pneumonia

This survival benefit associated with antibiotic is similar regardless whether antibiotics are given orally or intravenously

Evidence from observational studies looking at antibiotics for pneumonia

Comfort was highest among those not treated with antibiotics

Evidence from observational studies looking at antibiotics for pneumonia

The most aggressive treatment approaches (intravenous therapy or hospitalization) were associated with the greatest discomfort.

What's the alternative for treating pneumonia in dementia?

So When Should Individuals Be Treated with Antibiotics

- If prolongation of life is the goal, initiation of antibiotics is reasonable to treat a suspected infection by using the least invasive route of administration and if possible, avoiding hospitalization
- If comfort is the main goal, with a preference to forgo antimicrobials, symptoms should be treated in the nursing home

What About Hospice?

What about hospice?

Hospice in those with dementia has been associated with:

- improved pain management
- less aggressive care at the end of life
- fewer unmet needs during the last 7 days of life
- greater satisfaction among family members with end-of-life care
- more likely to die in their location of choice and less likely to die in the hospital

Medicare Hospice Benefit Guidelines for Determining Prognosis in Dementia

- To be eligible for hospice, patients must meet both of the following criteria:
  - Functional Assessment Staging (FAST): Patient must be at or beyond stage 7c and show all of the features of stages 6a-7c.
  - Medical conditions: Patients must have had at least 1 of the listed medical conditions over the prior year.

Functional Assessment Staging (FAST)

- Stage 6d: Incontinent of urine occasionally or frequently
- Stage 6e: Incontinent of bowel occasionally or frequently
- Stage 7a: Speech limited to fewer than 6 intelligible words during an average day
- Stage 7b: Speech limited to a single intelligible word during an average day
- Stage 7c: Unable to ambulate independently
- Stage 7d: Cannot sit up independently
- Stage 7e: Cannot smile
- Stage 7f: Cannot hold head up independently

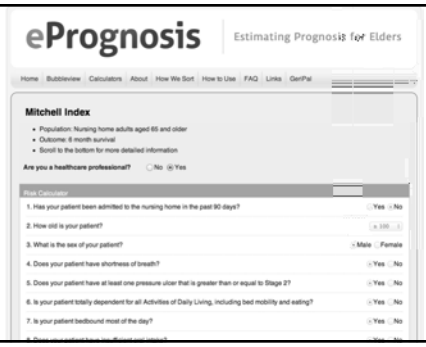
Hospice Criteria: At least 1 of these medical conditions over the prior year

- Aspiration pneumonia
- Pyelonephritis or other upper urinary tract infection
- Septicemia
- Decubitis ulcer, multiple, stage 3-4
- Recurrent fever after treatment with antibiotics
- Eating problems such that fluid or food intake is insufficient to sustain life (or, if tube fed, weight loss 10% over prior 6 months or serum albumin 2.5 g/dL)

Other Prognostic Tools: ADAPT

Table 1. ADEPT Scoring in Nursing Home Residents With Advanced Dementia (N = 606)

Characteristic	No. (%) of Nursing Home Residents	Points in Risk Score
Nursing home stay <90 d	29 (4.79)	3.3
Age, y (per 5-y increment)		
65-69	7 (1.16)	1.0
70-74	34 (5.61)	2.0
75-79	61 (10.07)	3.0
80-84	136 (22.44)	4.0
85-89	171 (28.22)	5.0
90-94	129 (21.29)	6.0
95-99	56 (9.24)	7.0
≥100	12 (1.98)	8.0
Sex, male	110 (18.15)	3.3
Shortness of breath	36 (5.94)	2.7
≥1 Pressure ulcers at ≥ stage 2	33 (5.45)	2.2
Activity of daily living score = 28[a]	256 (42.24)	2.1
Bedfast most of day	59 (9.74)	2.1
Insufficient oral intake[b]	252 (41.58)	2.0
Bowel incontinence[c]	537 (88.61)	1.9
BMI <18.5[d]	48 (8.28)	1.8
Recent weight loss[d,e]	68 (11.70)	1.6
Congestive heart failure	107 (17.66)	1.5



Four Questions to the Care Team

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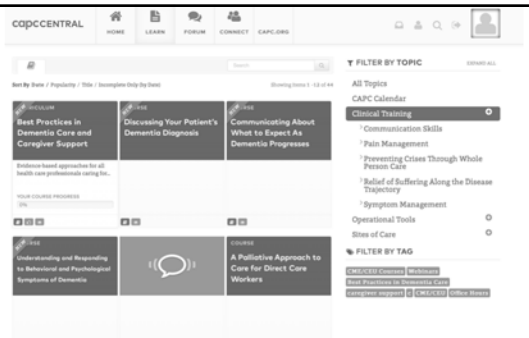
How should we address his agitation?

How should we address his weight & decreased oral intake?

How should we manage his swallowing problems?

How should we treat future infections?



Interprofessional Dementia Curriculum

- Discussing Your Patient's Dementia Diagnosis
- Communicating About What to Expect as Dementia Progresses
- Understanding and Responding to Behavioral and Psychological Symptoms of Dementia
- Supporting the Caregivers of People Living with Dementia
- Planning for the Future with People Living with Dementia and their Caregivers
- Addressing Mood and Sleep Disturbances for People Living with Dementia
- Addressing Swallowing Disorders, Pain, and Medical Decision-Making for People Living with Dementia

Questions?

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